



advice and support for older age

**Independent
Age**

Factsheet

Living with dementia

Being diagnosed with dementia can come as a shock. This factsheet explains more about the different types of dementia and the help available to you to support and maintain your independence. It also contains helpful information about dementia for your family and carers.

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Independent Age provides advice to help people claim benefits, access social care and stay independent at home. Our local volunteers provide friendship visits and calls for lonely older people. To find out how Independent Age can help you, call us FREE on **0800 319 6789** or visit **independentage.org**



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The information in this factsheet applies to England only. If you're in Wales, contact Age Cymru (0800 022 3444, agecymru.org.uk) for information and advice. In Scotland, contact Age Scotland (0800 470 8090, agescotland.org.uk). In Northern Ireland, contact Age NI (0808 808 7575, ageni.org).

1. What is dementia?

There are over 800,000 people in the UK who live with dementia. The term dementia is used to describe the symptoms of a number of different diseases or conditions that cause the progressive decline of your brain. Dementia can often affect your ability to:

- Remember
- Learn
- Think and reason
- Solve problems
- Speak and find the right words

Dementia may also cause:

- Confusion
- Depression and anxiety
- Personality and behaviour changes
- Struggles with planning and daily activities

Sometimes the symptoms of dementia develop slowly, while at other times it can develop suddenly and progress quickly. In either case, the effect on the person with dementia, their family and carers can be very distressing.

Although dementia is more likely to happen the older you get, it is not a normal or inevitable part of ageing.

At the moment there is no cure for dementia, although treatments and medication are available that can help slow and manage its progression.

Good to know

Dementia-like symptoms can have other causes, such as a chest or urinary infection, dehydration, side-effects of medication, depression, stress or vitamin deficiencies. It's important to speak to your GP if you're worried so they can run tests to find out what might be causing the symptoms.

2. Types of dementia

There are many different types of dementia. You can also have more than one type of dementia at the same time, which is sometimes called mixed dementia.

The most common types of dementia include:

Alzheimer's disease: A disease that causes disconnections between nerve cells in the brain and ultimately causes brain cells to die. This leads to a progressive decline in mental ability as the damage can spread to different parts of your brain.

Vascular dementia: Vascular dementia is caused by damage to the blood vessels that carry oxygen to the brain. It can be caused by strokes or by diseases of the small blood vessels in the brain.

Dementia with Lewy bodies (DLB): This is a physical disease of the brain. Lewy bodies are deposits of proteins in the brain. Over time, they lead to a loss of brain tissue and nerve cells.

People who have DLB will show symptoms associated with Alzheimer's disease and Parkinson's disease and may therefore be misdiagnosed. It is important that it is diagnosed correctly as people with DLB can react badly to certain medications.

Fronto-temporal dementia: Fronto-temporal dementia occurs when there is damage to the nerve cells in the frontal and/or temporal lobes in the brain. The brain tissue in these lobes can also shrink, affecting language, personality and behaviour. It can be called frontal-lobe dementia or Pick's disease. Fronto-temporal dementia is rare but is more common in people aged 45-65.

Other types of dementia

Rarer causes of dementia can include:

- Creutzfeldt-Jakob disease

- Huntington's disease
- Parkinson's disease
- HIV
- Multiple sclerosis
- Korsakoff's syndrome (associated with alcoholism)
- Head injuries

More information about the less common types of dementia, can be found in the Alzheimer's Society factsheet 'Rarer causes of dementia' (0300 222 1122, alzheimers.org.uk).

Mild cognitive impairment (MCI)

Mild cognitive impairment (MCI) is not a type of dementia but if you have MCI you have a higher likelihood of developing dementia. MCI includes minor problems with memory, concentration, problem-solving, planning, depth perception, language and learning new skills. However, these symptoms will not be severe enough to be counted as dementia. If you think you have MCI, speak to your GP.

3. Symptoms of dementia

Dementia symptoms vary from person to person and will often depend on the type of dementia that you have. Common symptoms include:

- Memory loss: you may become more forgetful, particularly about the recent past or people's faces and names
- Difficulty with planning: activities that require organisation and planning may become challenging
- Language problems: you may find it difficult to express yourself, understand other people or remember certain words or names
- Loss of ability to learn new skills: dementia can make it difficult to learn how to use a new piece of equipment, for example
- Poor mental health: you may experience depression, anxiety or mood swings
- Loss of judgement: you may become less able to judge the risks you face
- Orientation problems: you may get lost in familiar places or lose track of the time and date
- Vision problems: you may find it harder to see objects if they are a similar colour, struggle to detect movement or have problems with depth perception

As the disease progresses, you may also experience:

- Mobility problems: you may find it hard to keep your balance, be more unsteady on your feet and your movement may become slower

- Changes to behaviour and personality: depending on the type of dementia you have, this can include becoming more aggressive or losing some inhibitions
- Hallucinations and delusions: you may see things and people who are not there, or believe things that aren't true
- Difficulties with personal care: you may find it difficult to complete tasks in the correct order and need help preparing meals, washing, dressing and going to the toilet
- Incontinence: You may not recognise the need to use the toilet, or be able to locate or use the toilet
- Weight loss: You may find it more difficult to eat on your own or swallow. You may also lose your appetite. This can lead to weight loss.

For more information about the common symptoms for different types of dementia, see the NHS Dementia Choices website ([nhs.uk/Conditions/dementia-guide/](https://www.nhs.uk/Conditions/dementia-guide/)) or speak to the Alzheimer's Society (0300 222 1122, [alzheimers.org.uk](https://www.alzheimers.org.uk)).

4. Diagnosis of dementia

If you're worried about your memory or think that you or someone you know may have dementia, speak to your GP. They will be able to investigate the cause of your symptoms.

Sometimes dementia symptoms are caused by other treatable conditions, such as depression, thyroid gland disorders or a reaction to certain drugs. It is important that other possible causes are investigated.

Getting a diagnosis will help you get the right treatment, care and support, which can help you live independently and well with dementia.

What will your GP do?

It can be difficult to diagnose dementia, so your GP may use a range of tests. This can include:

- Taking a medical history – asking you about your symptoms and when changes started to happen
- Blood tests
- Exercises to test your mental abilities

Your GP may then refer you to a specialist such as a psychiatrist who specialises in the care of older people or a neurologist. They may be based in a memory clinic. The specialist may arrange a scan which will look for evidence of strokes, brain tumour, blood vessel damage or shrinking of brain tissue.

You may need to visit the specialist or memory clinic over the course of a few weeks, or a community psychiatric nurse (CPN) may visit you at home.

If you are diagnosed with dementia, further appointments and tests will be arranged with your GP and/or the specialists. The

appointments might explore appropriate treatments and monitor how the symptoms are progressing.

Good to know

NHS Choices ([nhs.uk/Conditions/dementia-guide/Pages](https://www.nhs.uk/Conditions/dementia-guide/Pages)) suggests asking your doctor the following questions:

- What type of dementia do I have?
- What are the tests or investigations I should have?
- How long do I have to wait until I have the tests?
- How long will it take to get the results of these tests?
- What will happen after I get the results?

You can get more advice about getting a diagnosis for dementia from the Alzheimer's Society (0300 222 1122, alzheimers.org.uk).

5. What help is available for people with dementia

Living with dementia can cause stress, financial hardship and a sense of isolation. It's important to get as much support as possible.

Support from the NHS

If you have symptoms of dementia, your GP should refer you to the local hospital's psychiatrist for older people or a local memory clinic. If you're diagnosed with dementia, the psychiatrist will advise you about medication that might help to control the condition or slow down its development.

You may also receive other services, such as:

- Support from a community psychiatric nurse (CPN) or Community Mental Health Team for advice, specialist care and/or treatment
- Talking therapies such as counselling, Cognitive Behaviour Therapy (CBT) or psychotherapy to help you deal with the diagnosis, or treat depression or anxiety
- An Admiral Nurse – a nurse specialising in dementia who can offer practical advice and emotional support, and be a single point of contact for health services. Find out if you have an Admiral Nurse in your area by contacting Admiral Nursing Direct (0800 888 6678, dementiauk.org)
- Home visits from district nurses for nursing care, such as changing dressings or giving medication

If you would like more information about accessing any of these services, speak to your GP.

If you have dementia and/or other complex health needs, the NHS may be able to fully cover the cost of your care at home

or in a care home. This funding is called NHS Continuing Healthcare and, if you are assessed as being eligible, is arranged by your Clinical Commissioning Group (CCG). For more information, see our factsheet Continuing Healthcare: should the NHS be paying for your care? or call our Helpline (0800 319 6789, independentage.org).

Support from your council

If you need some additional care and support, you have a right to a needs assessment from the adult social care team at your council. If you're eligible for support, they may be able to provide support services such as personal and home care, meals at home, day centres, a laundry service or cleaning.

For more information about getting a needs assessment, see our factsheet Assessment and care services from your local council in England. For more information about services you may be able to receive, see our factsheet Help at home: What may be available in your local area (0800 319 6789, independentage.org).

You may also receive other services, such as:

- An Occupational Therapy assessment to arrange equipment or adaptations that can keep you independent at home. For more information see our factsheet: Adapting your home to stay independent (0800 319 6789, independentage.org)
- Telecare, technology-based equipment such as pendant alarms to call for help if you fall or medication reminders that sound an alert when it's time to take a tablet. For more information, read our factsheet Telecare and telehealth: what it is and how to get it (0800 319 6789, independentage.org).

If you are caring for someone with dementia, see sections 10 and 11 for the help you may be eligible for.

Independent advocacy

If you are living with dementia and can no longer make decisions about your finances, health or care you may benefit from the support of an independent advocate. This is someone who can act in the person's best interests, making sure their opinions and wishes are taken into consideration.

An independent advocate may be particularly helpful if there's a conflict of interest, such as a dispute among family members as to the best care for a relative, or a disagreement about care decisions between the older person and the council.

An independent advocate can try to establish the wishes and needs of the older person and represent their points of view to the professionals involved. For more information, see our factsheet Independent advocacy (0800 319 6789, independentage.org).

Support from the voluntary sector

Many charities and voluntary organisations provide services such as advice, advocacy or social activities to support people with dementia and their carers.

If you have received a diagnosis of dementia, you may want to take a look at the following organisations:

The Alzheimer's Society (0300 222 1122, alzheimers.org.uk)

Provides help and support to people with dementia and those caring for them. They produce a wide range of booklets and guides on dementia, and have a national helpline offering specialist advice. They have a network of local branches which offer a range of services, such as advice and support groups for carers. Contact the central office for details of your local office.

Dementia UK (0845 257 9406, dementiauk.org)

Offers specialist support through their Admiral Nurse helpline. They work with people with dementia and their carers and families to provide specialist practical and emotional support.

Dementia Connect (alzheimers.org.uk/local-information/dementia-connect/)

An online directory of services for people living with dementia. It includes over 4,000 local information and support services.

Your area might have choirs, church services, film screenings, yoga or exercise classes, cycling groups and many other activities designed especially for people with dementia.

You could also speak to your local library or council adult social care team about local support.

Age UK (0800 169 6565, ageuk.org.uk)

A national organisation with local Age UKs that often provide services such as good neighbour schemes, handyperson and gardening services, lunch clubs and advice services. Contact the national office for details of your local Age UK.

6. Financial support for people with dementia

People with dementia may need practical support with managing their finances. You may have extra expenses, such as paying for care, so it is important to make sure you're receiving all the benefits you're entitled to.

Disability benefits: Attendance Allowance and Personal Independence Payment

While people with dementia won't automatically qualify for a disability benefit just because of their condition, if you have care needs you may be eligible for help. Attendance Allowance is an important benefit for people with dementia.

It is paid to people aged 65 and over who need supervision to avoid putting themselves or others in danger, or who need help with personal care such as washing, dressing and going to the toilet. This benefit is not means-tested.

People under 65 can make a claim for Personal Independence Payment. This has replaced Disability Living Allowance for new claimants.

Good to know

If you receive Attendance Allowance or Disability Living Allowance / Personal Independence Payment, you might be able to get a reduction in your council tax bill. For more information, see our factsheet Council Tax Support and Housing Benefit (0800 319 6789, independentage.org).

For more information about these benefits, see our factsheets Disability Benefits: Attendance Allowance and Disability Benefits: Disability Living Allowance and Personal Independence Payment.

Getting more from your Pension Credit

If you receive Pension Credit, you might be eligible for extra money called a Severe Disability Premium. You can get this if:

- you also get a disability benefit
- you live on your own
- nobody is getting Carer's Allowance for looking after you.

For more information, see our factsheet Pension Credit (0800 319 6789, independentage.org).

Looking after your benefits

If you're getting benefits but can't manage the money yourself, it is possible for you to arrange for someone else that you trust to collect the money from your bank account. Your bank or building society can arrange this if you write to them.

If you lose mental capacity and haven't set up a Lasting Power of Attorney (see section 8), the Department for Work and Pensions (DWP) can arrange for someone else, known as an appointee, to manage your benefits for you. This will usually be a close relative. Find out more at gov.uk/become-appointee-for-someone-claiming-benefits.

7. Suitable accommodation for someone with dementia

While many people with dementia can live at home for a long time, there may come a time when you will need to move into specialist accommodation.

Sheltered housing and Extra Care schemes

In some areas, sheltered or extra care housing schemes have been set up to provide accommodation and support for people with dementia. You have the independence of your own home with a bit more on-site support from wardens or carers.

For information on local schemes, see our factsheets Housing options in later life and Extra Care Housing (0800 319 6789, independentage.org). You can also contact your local council or the Elderly Accommodation Counsel (0800 377 7070, housingcare.org).

Care homes

Many residential care homes or nursing homes cater specifically for the needs of people with dementia. You can get a list of local dementia care homes from the CQC website (cqc.org.uk) or from the Elderly Accommodation Counsel (0800 377 7070, housingcare.org). The Alzheimer's Society can also provide you with a list of specialist care homes (0300 222 1122, alzheimers.org.uk).

Good to know

You can read the past inspection reports of care homes in England by contacting the Care Quality Commission (03000 61 61 61, cqc.org.uk).

Looking at these reports may help you choose a care home. It may be possible to have a trial stay at the care home to see if it would be suitable.

To do...

If you care for someone with dementia and they need to move into a care home, contact their local council to request a needs assessment. If they are assessed as needing to go into a care home, they will also have a financial assessment to decide how much they will have to pay towards their care home fees. For more information, see our factsheet [Paying Care Home Fees](#) (0800 319 6789, independentage.org). You might also find our [Wise Guide: Choosing a care home](#) useful. Call 0800 319 6789 to order your free copy.

8. Making decisions when you have dementia

If you or someone you know has dementia, you may hear health and social care professionals talk about 'mental capacity'. Mental capacity means having the ability to understand, retain and use information in order to make and express decisions about your life

If you have been diagnosed with dementia this does not automatically mean that you lack mental capacity. However, there may come a time when the progression of your condition means that you are no longer able to make decisions about your finances, health or welfare.

It's a good idea to appoint a trusted person to make decision on your behalf, should this happen.

Lasting Power of Attorney

A Lasting Power of Attorney is a legal document giving someone you trust the right to make decisions on your behalf should lose mental capacity. You must arrange this while you still have mental capacity.

There are two types of Lasting Power of Attorney:

- Property and financial affairs — which lets someone make decisions about your money and property
- Health and welfare — which lets someone make decisions about your personal welfare and healthcare

To set up a Lasting Power of Attorney, you will need to complete and register a form with the Office of the Public Guardian (0300 456 0300, gov.uk/power-of-attorney/make-lasting-power).

Good to know

The property and financial affairs LPA can be used immediately if you wish, while the health and wellbeing LPA can only be used if you lose mental capacity. For more information, see our factsheet *Managing my affairs if I become ill* (0800 319 6789, independentage.org).

Advance statements and advance decisions

An advance statement lets you explain your wishes for any care you might receive in the future. It's also a way of explaining your beliefs and values, and what would be important to you if you could no longer make decisions for yourself. It can act as a guide to your family and healthcare professionals involved in your care.

An advance decision is a way to refuse treatment or care if there comes a time when you're unable to make or communicate your decision. You could write an advance decision to make sure your doctors and family know what treatment or care you wouldn't want to receive in certain circumstances in the future. If it is set up correctly, an advance decision is legally binding.

For more information about creating an advance statement or advanced decision, see our factsheet *Managing my affairs if I become ill* (0800 319 6789, independentage.org).

Becoming a deputy

If you care for someone with dementia, you may find you need to make some decisions on their behalf if they can't decide or communicate for themselves. If they haven't already set up an LPA, you can apply to the Court of Protection to become a deputy. This can be a lengthy and expensive process so it's a good idea to get an LPA in place while the person still has mental capacity.

You will need to complete a number of application forms when applying to become a deputy. This will include an Assessment of Capacity form, which requires a GP, psychiatrist, speech and language therapist, social worker or similar professional to conduct a formal capacity assessment for the person you would like to become a deputy for.

For more information about becoming a deputy, see our factsheet *Managing my affairs if I become ill* (0800 319 6789, independentage.org) or contact the Office of the Public Guardian (0300 456 0300, gov.uk/become-deputy/overview).

9. Dementia and the Mental Health Act

Occasionally, a person with dementia may behave in such a way that it puts themselves or those around them at risk. If this occurs, it may be necessary for them to be hospitalised while they are assessed or treated. The person with dementia can voluntarily attend in-patient hospital treatment, or can be compulsorily detained under a section of the Mental Health Act against their wishes. You may have heard this called 'being sectioned.'

If you think someone with dementia needs to be detained in hospital, contact the local mental health team, your GP or call the emergency services if the situation is urgent. You may also find it helpful to read the Alzheimer's Society's factsheet *The Mental Health Act 1983 and guardianship* to find out more (0300 222 1122, alzheimers.org.uk).

10. Caring for someone with dementia

There are over 670,000 people in the UK caring for someone with dementia.

Caring for someone with dementia will often have a big impact on your life. You may feel resentment, frustration, anger and guilt. These feelings are normal and it's important to remember there's no right or wrong way to feel. You may find your caring role also brings rewarding and positive moments.

Getting practical support

Anyone who cares for a friend or relative has a right to a carer's assessment from their local council. It doesn't matter how much care you provide to someone – if you feel that you could benefit from some support, you are entitled to an assessment.

The assessment will look at what support you need so that you can continue in your caring role. The council must consider support such as:

- practical help with things such as housework or gardening
- support to improve your health and wellbeing, such a gym membership
- training to feel more confident in your caring role, such as moving and handling training
- emotional support from a local carers group, for example
- breaks from caring during the day or throughout the year
- travel assistance for you or the person you care for

You may also be entitled to a benefit called Carer's Allowance.

For more information, see our factsheet Carers: what support is available (0800 319 6789, independentage.org).

Getting emotional support

It is important that you look after your emotional wellbeing and mental health. If you're feeling low, anxious or stressed, consider talking to someone about how you're feeling such as a friend, family member or your GP.

It may help to speak to people who are in similar circumstances to you. Carers UK (0808 808 7777, carersuk.org) provides advice and support to carers. It also runs support groups where you can talk to people in similar circumstances. The Alzheimer's Society has an online support forum called Talking Point (alzheimers.org.uk/talkingpoint).

11. Practical tips for caring for someone with dementia

Communicating with someone who has dementia

Sometimes it can be difficult to communicate with someone who has dementia because they can get confused or be unable to clearly express what's on their mind. There are simple things that you can do that may help, such as making sure that any hearing aids, glasses or dentures they have are working properly.

Speak clearly and slowly to the person with dementia rather than raising your voice. Alternatively, they may find it easier if you write down what you want to say. Offering simple choices rather than leaving questions open-ended can also be effective.

The Alzheimer's Society has a factsheet called Communicating which has more detailed advice (0300 222 11 22, alzheimers.org.uk).

Past memories

Talking about the past can be a valuable experience for both you and the person with dementia. Although dementia is responsible for memory loss, it is usually short-term memory that is most severely affected. Reminiscence therapy focuses on older memories and it can be comforting for both of you to talk about the past and share experiences. Using old photographs, postcards, music and even visits to places, can help with this. However, in rare cases, recalling memories can cause distress. Call the Alzheimer's Society for advice (0300 222 1122, alzheimers.org.uk).

Helping with personal care

Someone with dementia may need reminders or help to carry out personal care tasks such as washing and drying or getting

dressed. If possible, encourage the person you are caring for to do as much as possible for themselves.

For example, laying out clothes in the right order can make it easier for a person with dementia to dress themselves. Slip-on shoes and easy-fastening clothes (such as those with Velcro instead of buttons) can make dressing easier. Try to support the person with dementia to choose what they want to wear.

It may feel difficult or inappropriate for you to supervise or wash the person with dementia. If so, speak to the council to request a needs assessment and ask about the possibility of a home care worker to help with bathing.

Eating

Some people with dementia lose their appetite or find it difficult to use cutlery or swallow food. Eating may be easier for them if the table is laid simply with just one set of cutlery, for example. You can also buy specially designed cutlery to make eating easier. The Disabled Living Foundation (0300 999 0004, dlf.org.uk) has information on different types of aids to help you eat and where you can get them.

If the person with dementia has problems swallowing, ask their GP for a referral to a speech and language therapist who specialises in swallowing problems. You should also ensure the person's dentures are fitted correctly, if they wear them.

People with dementia may also get restless or distracted during meal times. Meals should be unhurried and made at the same time each day. Avoid distractions, such as having the TV on or people coming and going during meal times. The person with dementia may need to be prompted to eat, but don't put pressure on them if they're getting distressed.

Continence

Incontinence can be a problem for someone with dementia. It is always important to check first that a treatable medical condition is not causing the incontinence by speaking to your GP. If the condition is not treatable, your GP can contact a local continence advisor or service. There are a number of aids available to help with incontinence, such as washable absorbent bed pads and incontinence pads which are available free from the NHS. You can get information and advice from The Bladder and Bowel Foundation's nurse helpline (0845 345 0165, bladderandbowelfoundation.org).

Walking

It is quite common for people with dementia to walk around or try and leave a room or their home. This can happen when the person is motivated to start something or go somewhere but can't remember what they intended to do. They may also be bored, restless or trying to keep up an older routine, such as walking to work or taking the children to school.

These symptoms may be worrying for the carer, especially if the person tries to leave their home. It may help to understand that the person with dementia may be searching for something rather than simply walking aimlessly. It may also help to make sure the person with dementia goes on regular accompanied walks or takes other forms of exercise. The Alzheimer's Society (0300 222 1122, alzheimers.org.uk) can offer further advice on wandering.

Aggressive behaviour

Some people with dementia show aggressive behaviour, either verbal or physical. This is a symptom of the disease, which can appear or disappear at any stage of the illness. Aggressive behaviour may be a reaction to something they feel frightened about. They may also be anxious or bored. A psychiatrist or

community psychiatric nurse (CPN) may be able to advise and help you manage aggression or agitation. The Alzheimer's Society (0300 222 1122, alzheimers.org.uk) can also provide advice on changes in behaviour and dealing with aggression.

12. Useful contacts

For general information, advice and support when dealing with dementia:

- Alzheimer's Society (0300 222 11 22, alzheimers.org.uk)
- Dementia UK (0845 257 9406, dementiauk.org)

For issues about the mental capacity of someone with dementia:

- Office of the Public Guardian (0300 456 0300, gov.uk/government/organisations/office-of-the-publicguardian)

For general support and advice for carers:

- Carers UK (0808 808 7777, carersuk.org)

This factsheet has been put together by Independent Age's expert advisers. It is not a full explanation of the law and is aimed at people aged over 60.

If you need this information in an alternative format (such as large-print or audio cd), call us on 0800 319 6789 or email advice@independentage.org.

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- take part in our annual raffle
- donate in memory of a loved one
- remember Independent Age in your will and benefit from our Free Wills offer to supporters.

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